Longevity and Causes of Death in Persons with Intellectual Disabilities Resident at Rideau Regional Centre (1979 - 2008): Implications for Community Care

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The Present Study

Characterize mortality patterns with Rideau Regional Centre in relation to implications for community-based care.
Two Questions often raised About a Death:

1. Was it premature?
   - Longevity in Canada (2010): male 78.3 years, females 83.0 years

2. Was the cause unusual?
   - Usual causes of death in Canada (2008):
     - Cancer: 25%
     - Cardiovascular diseases: 20%
     - Respiratory diseases: 6%

Death in Persons with ID

- Often premature – deaths particularly common before age 30
- Pattern of causes is atypical
  - respiratory infections
  - “sudden deaths”
  - cancer

A Further Concern Regarding Deaths in ID Population

- 70–80% increase in death rates in those moving from institutions to the community
In The Event of a Death

**Primary care physicians:**
- Contact next of kin
- Contact Coroner
- Complete a Mortality Summary

**Coroner:**
- Complete report & arrange for postmortem examination

**Pathologist:**
- Conduct postmortem examination and Pathology Report

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**Health Care at Rideau Regional Centre**

**ROLE OF DSW STAFF:**
- Observations
- Administration of Medications

**ROLE OF AREA NURSES:**
- Screening
- Coordination
- Prevention
- Treatments

**ROLE OF PRIMARY CARE PHYSICIANS:**
- Annual Health checks
- Regular clinics
- Infirmary care
- Transfers for specialized care

**OTHER:**
- Dental
- Pharmacy
- Lab
- X-ray
- Speech language therapy
- O.T.
- Physiotherapy
- Psychology
- Infirmary
Sources of Data 1979 – 2008

1) 275 MORTALITY SUMMARIES
   - Age, gender
   - Level of MR
   - Other problems: CP, Epilepsy, Down’s
   - Cause of death (clinical impression)

2) 48 PATHOLOGY REPORTS
   - Cause of death (pathology impression)
   - Significant contributing factors

Table 2
GENDER* AND MEAN AGE AT DEATH (YEARS) BY INTERVAL

<table>
<thead>
<tr>
<th>Interval</th>
<th>Age Range</th>
<th>Mean Age</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Male</td>
<td>Female</td>
</tr>
<tr>
<td>1979 – 88</td>
<td>9 – 45</td>
<td>11 – 79</td>
</tr>
<tr>
<td>1989 – 98</td>
<td>18 – 80</td>
<td>20 – 80</td>
</tr>
<tr>
<td>1999 – 2008</td>
<td>34 – 76</td>
<td>28 – 86</td>
</tr>
</tbody>
</table>

*164 males, 111 females

Table 3
LEVEL OF INTELLECTUAL IMPAIRMENT* AND AGE AT DEATH (YEARS) BY INTERVAL

<table>
<thead>
<tr>
<th>Interval</th>
<th>All Subjects</th>
<th>Profound</th>
<th>Severe</th>
<th>Moderate</th>
<th>Mild</th>
<th>Unspecified</th>
</tr>
</thead>
<tbody>
<tr>
<td>1979 – 88</td>
<td>21.8</td>
<td>12.6</td>
<td>20.0</td>
<td>36.0</td>
<td>34.0</td>
<td>28.3</td>
</tr>
<tr>
<td>1989 – 98</td>
<td>46.0</td>
<td>46.1</td>
<td>50.6</td>
<td>45.0</td>
<td>59.3</td>
<td>--</td>
</tr>
<tr>
<td>1999 – 2008</td>
<td>56.5</td>
<td>53.8</td>
<td>58.6</td>
<td>61.0</td>
<td>69.9</td>
<td>50.4</td>
</tr>
</tbody>
</table>

* 164 profound, 58 severe, 59 moderate, 10 mild, 33 unspecified
Table 4
CLINICAL GROUP* AND MEAN AGE AT DEATH (YEARS) BY INTERVAL

<table>
<thead>
<tr>
<th>Interval</th>
<th>All Subjects</th>
<th>Down Syndrome</th>
<th>Epilepsy</th>
<th>Cerebral Palsy</th>
<th>Both Down Syndrome and Cerebral Palsy</th>
</tr>
</thead>
<tbody>
<tr>
<td>1979 - 86</td>
<td>31.8</td>
<td>29.6</td>
<td>31.6</td>
<td>28.5</td>
<td>28.6</td>
</tr>
<tr>
<td>1969 - 96</td>
<td>46.0</td>
<td>49.0</td>
<td>45.9</td>
<td>51.1</td>
<td>43.1</td>
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<tr>
<td>1969 - 2006</td>
<td>56.5</td>
<td>56.9</td>
<td>57.2</td>
<td>54.9</td>
<td>49.8</td>
</tr>
</tbody>
</table>

* Down Syndrome 58, Epilepsy 74, Cerebral Palsy 39, Epilepsy and Cerebral Palsy 54 (individuals may have more than one diagnosis)

Fig.1 DISTRIBUTION OF AGES OF DEATH

Table 5
NUMBER OF DEATHS CAUSE BY INTERVAL

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Respiratory Infections</td>
<td>43</td>
<td>26</td>
<td>22</td>
<td>10</td>
</tr>
<tr>
<td>Suicide</td>
<td>25</td>
<td>40</td>
<td>25</td>
<td>34</td>
</tr>
<tr>
<td>Malignant Neoplasms</td>
<td>8</td>
<td>12</td>
<td>5</td>
<td>9</td>
</tr>
<tr>
<td>Cardiac Failure</td>
<td>2</td>
<td>3</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>Diseases</td>
<td>1</td>
<td>1</td>
<td>7</td>
<td>6</td>
</tr>
<tr>
<td>Diabetes</td>
<td>1</td>
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<td>1</td>
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<tr>
<td>Other</td>
<td>1</td>
<td>2</td>
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<td>Other</td>
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Table 7
NUMBER OF DEATHS CAUSE BY INTERVAL

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<td>7</td>
<td>6</td>
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<td>1</td>
</tr>
<tr>
<td>Other</td>
<td>1</td>
<td>2</td>
<td>2</td>
<td>2</td>
</tr>
</tbody>
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Leading Causes of Death: General Population vs. RRC Study

**Canadian Population (2008)**
- Cancer 25%
- Cardiovascular disease 20%
- Respiratory disease 6%

**RRC Study (1979 – 2009)**
- Respiratory disease 34%
- Asphyxia 25%
- Gastrointestinal disorders/Cancer 9%

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**POST – MORTEM OBSERVATIONS**

<table>
<thead>
<tr>
<th>Age/Gender</th>
<th>Disability Profile</th>
<th>Medical Profile</th>
<th>Cause of Death</th>
<th>Neuropathologic Findings</th>
<th>Brain Weight</th>
</tr>
</thead>
<tbody>
<tr>
<td>28 M</td>
<td>Poly (Latex Glove)</td>
<td>Poly (Latex Glove)</td>
<td>Sudden cardiac death</td>
<td>Cerebral hemorrhage</td>
<td>1159 gms.</td>
</tr>
<tr>
<td>29 M</td>
<td>Fall</td>
<td>Fall</td>
<td>Sudden cardiac death</td>
<td>Cerebral hemorrhage</td>
<td>1195 gms.</td>
</tr>
<tr>
<td>52 M</td>
<td>Dementia</td>
<td>Dementia</td>
<td>Severe Alzheimer’s disease</td>
<td>Cerebral hemorrhage</td>
<td>1033 gms.</td>
</tr>
</tbody>
</table>

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**IMPLICATIONS FOR COMMUNITY-BASED CARE**

**CARE GIVERS/FAMILY/AGENCY**

- Awareness of health issues
- Training – first aid, use of medications
- Note and report incidents of ill health
- Vigilance regarding “high risk” situations
- Contribution to “Hospital Passports”
**IMPLICATIONS FOR COMMUNITY-BASED CARE**

**HEALTH CARE PROVIDERS**

- Include developmental disabilities in curricula for nurses, physicians, etc.
- Positive relationships with care-givers
- Awareness of Clinical Practice Guidelines
- Judicious use of consultants (neurology, psychiatry) etc.

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**IMPLICATIONS FOR COMMUNITY-BASED CARE**

**“SYSTEMS” ISSUES**

- Careful review of deaths
- Public health observatory

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**IMPLICATIONS FOR COMMUNITY-BASED CARE**

**“SYSTEMS” ISSUES**

- Implications of risks with “sudden death”
- Community nursing services (Ontario vs UK)
- Waiting list issues, ambulance response times
- Funding for “annual health checks”, regional teams
- Changes in death certificates
QUESTIONS?